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Physical activity participation in community dwelling stroke survivors

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1 Introduction

2 Stroke is a global health problem. Annually 16 million stroke events occur worldwide
3 and 62 million stroke survivors live with stroke consequences [1]. Stroke causes
4 motor and functional impairment, restricting participation in social and leisure
5 activities, negatively influencing survivors' quality of life [2]. Risk of stroke
6 recurrence is high, at 26% five years post-stroke [1].

7

8 Regular participation in physical activity (PA) can ameliorate recurrence, improve
9 functional mobility, walking capacity [3], muscle strength [3], bone density [4] and
10 quality of life [5]. Stroke guidelines recommend survivors undertake three aerobic,
11 flexibility and strengthening exercise sessions per week for health benefits [6]. In
12 response, post-rehabilitation exercise services have been developed, often led by
13 physiotherapists. Despite such developments, around 70% of survivors undertake
14 minimal post-rehabilitation PA [7], causing low fitness levels compared to age-
15 matched peers. This deconditioning compounds stroke effects, worsening physical
16 disability [6]. Understanding beliefs, attitudes, barriers and facilitators to PA
17 behaviour is therefore vital.

18

19 Previous qualitative studies and surveys highlight *pragmatic* and clinical barriers and
20 facilitators to PA, including physical effects of stroke, social and instrumental
21 support, transport availability, and costs [8-10], however beliefs and attitudes, which
22 are important determinants of PA, have not been fully explored after stroke [10] .

23 Existing evaluations of barriers to PA were conducted mainly with African American
24 populations [11], with survivors within other studies [12], members of existing stroke

groups [12] or conveniently selected ambulatory survivors [13-15]. These studies may not present sufficiently diverse perspectives to fully understand the challenges faced by survivors. Views of survivors purposefully selected to have diverse disabilities, age ranges and socio-demographic status should thus be elicited.

Physiotherapists frequently play a role in PA promotion after stroke. Our previous qualitative study shows that physiotherapists often see survivors' PA motivation as un-modifiable and report little expertise in addressing survivors' motivation and health behaviours [16]. Those views seem to influence how physiotherapists' promote PA with survivors; particularly their efforts to support survivors whom they believe have low motivation. Therefore, if physiotherapists are to successfully support stroke survivors to be active, they require the skills to fully understand and explore issues survivors face to participation in PA.

This study explored attitudes, beliefs, barriers and facilitators to PA of a purposefully selected sample of survivors, to seek to understand influences on PA participation.

Specific research questions were:

- What are stroke survivors' beliefs about the role and importance of PA in stroke recovery?
- What are survivors' experiences, beliefs and attitudes towards PA after rehabilitation and what meanings do they ascribe to PA?
- What barriers and facilitators to participation in PA do survivors experience? How do these influence decisions to engage in PA?

We also aimed to develop an explanatory model to enhance understanding of PA after stroke and to guide development of tailored, acceptable PA interventions within physiotherapists' scope of practice.

Methods

A qualitative design was used to explore stroke survivors' beliefs, experiences and barriers to PA [17, 18]. In-depth interviews allowed interviewees' responses to be probed and clarified, providing data grounded in interviewees' lives. We also conducted focus groups with carers and physiotherapists. Comparison between physiotherapists' and survivors' views is reported elsewhere [16].

East of Scotland Research Ethics Service granted ethical approval (reference 10/S1401/47).

Sampling and Recruitment

Community dwelling stroke survivors were eligible for participation six months after discharge from rehabilitation, if able to provide informed consent. We sampled by gender, age, physical disability and deprivation to capture views from survivors for whom these factors may have influenced PA participation [19].

Community stroke liaison nurses from two Scottish health boards sent invitation letters to 260 potential participants. The study researcher contacted ninety respondents by telephone for screening, and preliminary match to sampling criteria. The researcher (TO) was a female health psychologist experienced in qualitative

research in healthcare settings . Full screening for those matching sampling criteria was conducted at participants' homes before interview. Screening tools for sampling criteria [20-24] are described in Supplementary Information, Table A. Previous work [25] suggested we would reach the point at which no new ideas emerge with 30-40 participants; therefore target recruitment was 36 participants.

Data Collection

Face-to-face semi-structured interviews of one hour were conducted by TO at participants' homes, with 38 survivors. Two participants were interviewed using Talking Mats Framework [TMF]^{®*}, a communication tool adapted to match topic guides [26]. Interviews were audio recorded and TMF[®] interviews were video-recorded. All were fully transcribed.

Topic guide

The topic guide (see Supplementary Information, Table B) drew on psychological concepts known to influence health behaviours. Leventhal's Common-Sense Model of Illness Representation (CSM) suggests beliefs about cause and consequences of illness inform how individuals develop coping strategies and action plans to deal with their illness, and how they appraise expected outcomes [27]. We examined these concepts in relation to stroke and physical activity. We also drew on the concept of self-efficacy within Bandura's Social Cognitive Theory, concerned with confidence to achieve expected outcomes [28]. Self-efficacy is known to influence uptake and maintenance of PA [6]. Although drawing on the concepts, we were not limited by them, and also examined barriers and facilitators more generally, aiming to maintain

an essentially inductive approach. Emerging issues were included in subsequent interviews, maintaining an inductive approach. Documented field-notes also informed data interpretation.

Data Analysis

Framework Approach [29, 30] guided data analysis and NViVO 9 software facilitated data organization. Framework was selected because it is particularly useful for conducting applied qualitative research and for analysis by teams of researchers. TO read and coded transcripts according to a) initial research questions b) explanatory theoretical concepts described above. She was also alert to emergent issues. Two additional researchers [JM, TK] applied coding to nine transcripts each, providing inter-coder verification and establishing agreement about the coding framework. We opted to review the eighteen transcripts to ensure participants across the sampling framework were represented, and that half the transcripts were reviewed by two researchers. Researchers next aggregated codes into higher order themes informed by research questions, apriori theoretical concepts and emerging issues. The thematic framework was applied to all transcripts by TO. Themes were agreed and added as they emerged from subsequent interviews until all transcripts were indexed. Data were summarised and inserted into thematic charts organised by case, major themes and sub-themes[29] . The final thematic framework was refined by agreement between all researchers [JM, TO, TK, SJ, BW]. Constant comparison across themes and between cases ensured systematic data comparison for mapping and refinement of higher order concepts[29]. New relationships between concepts were sought until our final conceptual model was defined. Where disagreements

occurred, researchers clarified concepts and searched transcripts to inform accurate text interpretation. Analytical themes are presented in Supplementary Information, Table C, and in a final conceptual model Figure 1. A final group session with stroke survivors [n=5] and carers (n=4) established credibility, accuracy and completeness of our interpretation [18].

Results

Participant Characteristics

We recruited 19 male and 19 female participants aged between 23 and 85 years, and 8 months to 30 years post-stroke (Table 1). Twenty-one participants were categorised by Carstairs Index as having high socioeconomic status, and Barthel Index scores ranged from 60 to 100, denoting diverse physical disabilities.

Findings

Barriers and facilitators coalesced around motivation (defined as ‘desire to be active’) and capabilities (defined here as ‘resources to be active’). These concepts emerged from survivors’ attitudes and experiences of PA, and their physical, social and environmental context. Survivors appeared to experience motivation and capability as synergistic or dissonant, and interaction between motivation and capability seemed to determine survivors’ PA participation. Dissonance occurred when motivated survivors had limited capability for PA, causing frustration, or, when survivors had capability but little desire for activity. Confidence to achieve goals and determination to overcome barriers acted as activity catalysts when other influences

were synergistic. Below, we explain concepts before illustrating in an explanatory model their influence on PA participation.

Influences on Physical Activity Motivation

Beliefs, experiences and attitudes to PA and stroke recovery

Beliefs and attitudes ascribed to PA reflected its value relative to stroke recovery, which in turn influenced motivation.

PA as incidental to recovery

Many survivors viewed stroke recovery as a natural process over which they had little control (Table 2, quote a). Some survivors, often older, only participated in PA that was integrated and incidental to everyday living. Intentionally engaging in PA to enhance recovery was uncommon, and activity was associated with “getting by” in everyday life (Table 2, Quote b). Attitudes stemmed from the mental and physical effort of PA that was additional to already difficult lives (Table 2, Quote c).

Insert Table 2 about here

PA as central to recovery

Other survivors prioritised PA as structured, planned exercise. They were often younger, motivated to participate in organised exercise, with clear expectations of physical benefits, despite disability (Table 2, Quote d). They attributed stroke to

169 medical conditions or lifestyle behaviours that could be ameliorated by PA.

170 Consequently, PA appeared important for recovery and future prevention, and

171 benefits were relevant to post-stroke life.

172
173 *PA as a social facilitator*

174 Some survivors, often younger, expressed social and occupational drivers for

175 recovery, including family, work, and social roles, representing desire for fulfilling

176 lives. PA was thus prioritised for its potential to facilitate participation in wider life

177 roles despite effort involved (Table 2, Quote e). Other survivors expressed more

178 direct social benefits of PA. These survivors enjoyed PA, viewing it as pleasurable

179 activity and were motivated by return to the social sense of self that it offered (Table

180 2, Quote f) or because it passed time (Table 2, Quote g).

181
182 *Role of pre-stroke PA behaviour*

183 These beliefs were frequent if survivors had undertaken pre-stroke PA, saw it as part

184 of their identity and *expected* physical benefits of PA to influence recovery, (Table 2,

185 Quote h). However, attempts to return to pre-stroke activities were sometimes

186 undermined by frustration resulting from lost skills. Failure to achieve expected

187 benefits sometimes led to loss of enthusiasm (Table 2, Quote i). Conversely,

188 survivors who had never been active did not see PA as part of their identity, making

189 purposeful engagement unlikely (Table 2, Quote j).

190
191 In summary, beliefs about stroke cause, recovery, enjoyment and expectations of

192 benefits influenced desire, or motivation to participate, beyond daily tasks.

Although physical disability influenced actual activity, many survivors were motivated, irrespective of disability, if other drivers were strong.

Perception of Capability for Physical Activity

Translation of motivation into actual activity appeared dependent on perceptions of capability for PA. Capability stemmed from appraisal of internal and external influences representing barriers or facilitators to activity. *Intrinsic influences* included physical effects, emotional and cognitive responses to stroke, and confidence in an individual's ability to engage in any specific activity. *Extrinsic influences* included support from others, and environmental barriers or facilitators. These influences are described below with exemplary quotes in Table 3.

Insert Table 3

Intrinsic Influences on capability

Direct effects of stroke

Physical effects of stroke, including weakness and balance problems, influenced perceived capability, presenting barriers to activity. Several survivors also reported that communication difficulties reduced their confidence to attend organised classes. Physical effects of stroke were often compounded by co-morbidities or fatigue, which limited capability, preventing even motivated survivors from being active (Table 3, quote a).

217 ***Cognitive and emotional effects of stroke***

218 *Mood*

219 The influence of mood on survivors' PA stemmed sometimes from post-stroke
220 depression and in some cases from previous mental health problems. Many
221 survivors experienced low post-stroke mood, or depression, negatively influencing
222 perceived capability for PA. This was sometimes related to perceptions of physical
223 and social impacts of stroke, (Table 3, quote b). In contrast, some survivors with pre-
224 existing mental health problems prioritised PA to maintain and improve mood, as
225 they had done pre-stroke, and they saw achieving and maintaining capability for PA
226 as vital to their wellbeing.

227

228 *Fear*

229 Fear of negative consequences of PA also influenced perceived capability for PA and
230 could prevent survivors from translating motivation into action. Fear often stemmed
231 from perceptions of poor balance and possibility of falling (Table 3, quote 5c). For
232 others, fear of another stroke caused by PA was weighed against concern of
233 inactivity causing another stroke. This led to careful consideration before committing
234 to PA. Development of coping strategies around fear was important (Table 3, quote
235 5d).

236

237 *Embarrassment*

238 Embarrassment stemmed from survivors' self-consciousness about exercising in
239 public places and how others might perceive them. The gym environment, with
240 mirrors and emphasis on conforming to images of physical perfection exacerbated

embarrassment and many survivors were uncomfortable exercising or even going there (Table 3, quote e).

Psychological influences

Confidence

Confidence commonly influenced PA participation. Where survivors felt confident to try activities, physical disabilities presented doubts about success, generating caution. Where attempts at activity were unsuccessful, confidence was lowered, perceived capability for PA undermined, and motivation was lost. In this way, capability and motivation were linked (Table 3, quote 5f). Conversely, survivors became confident by mastering difficult activities. Success translated to confidence in general capability to be active, enhancing motivation (Table 3, quote g).

Determination

Determination to overcome stroke and recover sense of self was linked to confidence. This expression of willpower enhanced perceived capability and motivated some survivors, even those with severe disability, to engage in activity to overcome stroke. In turn, confidence or self-efficacy improved and motivation to continue was enhanced. Younger survivors with family commitments commonly expressed determination, but older survivors also demonstrated determination for recovery (Table 3, quote h). Some older survivors simply accepted their situation however (Table 3, quote i). Their capability *and* motivation were affected by co-existence of age, co-morbidity, disability and limited interest in PA.

265

266 **Extrinsic influences on capability**

267 ***Social Support***

268 *Role of Health Professionals*

269 Participants viewed health professionals, particularly physiotherapists as facilitators
270 of PA. However therapy could be facilitatory or frustrating. It was time-limited, and
271 self-management advice was not always provided. Frustration was common when
272 physiotherapists did not tailor self-directed exercises to survivors' disabilities (Table
273 3, Quote j). Conversely, effective self-management support for PA enhanced
274 survivors' capability and confidence (Table 3, quote k).

275

276 *Role of family members*

277 Family often provided instrumental support to enable motivated survivors to be
278 active. However survivors valued this support in different ways. Over-protective
279 family appeared to undermine survivors' autonomy, which sometimes led to
280 resentment (Table 3, quote l). Some family members were directive, which whilst
281 resented by some, spurred others to activity because it reflected normal interactions
282 within relationships (Table 3, quote m). Survivors valued caring approaches that
283 supported their autonomy to be active in ways they desired (Table 3, quote n).

284

285 *Role of other survivors*

286 Opportunities for PA with other survivors were valued and enhanced perceived
287 capability to be active. Other survivors provided moral support and were viewed as
288 role models for what could be achieved. Seeing others recover, provided survivors

with a frame of reference for their own recovery potential (Table 3, quote o).

However, some survivors, typically male, preferred to exercise alone, reporting this as their lifelong preference (Table 3, quote p).

Environmental Influences

Environmental barriers to PA stemmed from transport availability and accessibility (Table 3, quote q), lack of knowledge of opportunities, high costs of organised activity, inclement weather and inconvenient timing of opportunities (Table 3, quote r). These were pragmatic barriers to capability influencing whether participants shifted from motivation to activity.

Synergy and Dissonance between Motivation and Capability

Many survivors overcame pragmatic barriers to PA through adjusted expectations of what was possible (Table 3, quote s). However, where performance of previously valued activities was perceived unsatisfactory, dissonance between motivation and capability for PA could cause *frustration* (Table 3, quote t). In response, some survivors selected more achievable activities; others expressed determination to overcome barriers (Table 3, quote u); whereas those with fewer concrete beliefs about PA and recovery, just accepted limitations and frustration as part of post-stroke life (Table 3, quote v). In contrast, where capability and motivation were synergistic and barriers could be overcome, survivors chose to be active despite physical and other challenges (Table 3, quote w).

313

314 **Discussion**

315 Synergy and dissonance between motivation and capability appear critical to
316 understanding stroke survivors' attitudes to PA, as we illustrate in our explanatory
317 model (Figure 1). Our model (Figure 1) illustrates the dynamic nature of these
318 interactions and provides a framework to inform physiotherapists' understanding of
319 PA participation that will guide development of person-centred approaches
320 facilitating survivors' PA.

321

322 Although motivation and capability have been previously identified as influencing
323 post-stroke PA [15, 31] we believe our model provides a more nuanced explanation
324 of interactions between pragmatic and conceptual issues faced by survivors.
325 Findings suggest addressing survivors' beliefs about PA, by providing information
326 about its role in stroke recovery, coupled with motivational, behavioural and
327 pragmatic support to address capability, will enable physiotherapists to better
328 facilitate survivors' PA participation. The findings endorse recommendations that
329 skills to understand and support behaviour change should be within
330 physiotherapists' toolkit [32].

331

332 As predicted by Leventhal's model [27], which in part informed our topic guide,
333 survivors with few coherent beliefs about stroke cause, prevention and recovery
334 appeared least likely to prioritise PA, and least motivated to address barriers
335 influencing their capability for PA. This passive synergy between motivation and
336 capability meant they were unlikely to use PA as a coping strategy for recovery.

Others, whose stroke beliefs supported PA, created synergies between motivation and capability leading to PA participation, often despite limiting disabilities. Findings illustrate complex influences on survivors' motivation and illustrate why physiotherapists must understand how survivors' beliefs influence their behaviour.

Data also illustrated how confidence to overcome *pragmatic, environmental* barriers to PA, such as transport and negotiating leisure centres, appeared to influence perceived capability. Confidence to address barriers in turn enhanced *motivation* for activity, illustrating the synergistic relationships between motivation and capability. As we predicted, the finding aligns with Bandura's social cognitive theory [28], which proposes self-efficacy, or confidence to *successfully* undertake activities, determines motivation *and* translation of motivation into behaviour. Physiotherapists are important facilitators of PA after stroke [16, 33]. Our data suggests exploring survivors' self-efficacy for PA and finding activities survivors can successfully undertake despite disabilities, will enhance physiotherapists' facilitation of behaviour change.

Although not anticipated apriori, self-determination was an emergent theme within our analysis. Survivors with high determination reported being motivated to overcome diverse barriers to PA capability, leading to synergy between motivation and capability that facilitated activity. The finding aligns with Deci's self-determination theory [34] in proposing that autonomous determination for outcome achievement predicts sustained activity. Self-determination theory has been shown in a systematic review of motivational interviewing in physiotherapy to be a

successful way to improve adherence to physiotherapy-led PA in other conditions [32]. Our findings endorse the importance to physiotherapists of understanding the role played by self-determination in PA after stroke, and suggest this theory should also inform physiotherapists' assessment of survivors' attitudes and beliefs about PA, and the development of new tailored interventions to support survivors' PA.

Frustration occurred when survivors reported dissonance between high motivation and low capability. The finding aligns with another qualitative study involving five young stroke survivors, in suggesting frustration emerges from tension between desire for recovery and limitations imposed by stroke-related impairment [35]. For physiotherapists, ascertaining outcomes survivors want to achieve from PA, and addressing barriers to achievable goals may foster determination and generate synergy between motivation and capability. This may require physiotherapists to be creative in seeking activities that enable participation despite limited physical capability.

Age seemed to influence determination, with older survivors citing effort and old age as accepted limitations to capability. Such acceptance of age-related limitations may reflect adjustment to declining capabilities as life progresses [36, 37]. The challenge to physiotherapists is to promote PA by seeking to understand older survivors' motivation and tailoring strategies to address attitudes and barriers faced by older survivors.

Reflecting other qualitative studies, cost, transport, opportunities, and inclement weather were external barriers to capability [12, 38]. Congruently, systems wide approaches, drawing on socio-ecological models, linking health, social care, sport and leisure services, and design of accessible environments are necessary to provide accessible options for survivors irrespective of age, demographic status, weather and personal preferences [10, 33, 39]. Physiotherapists are key players in facilitating development of systems-wide approaches through their links between health, social care, leisure and public health [33]. Our model paves the way for physiotherapists to contribute to these larger systems by providing a dynamic, fine-grained evaluation of PA barriers faced by survivors.

Physiotherapists are key professionals for PA promotion after stroke. They therefore have responsibility to understand multi-layered barriers to physical activity facing survivors and how motivation and capability interact to influence survivors' PA. Applying the model to PA promotion after stroke, will better equip physiotherapists to understand why survivors choose to be active or not.

Implications for research, practice and policy

Future research should develop and test tools to assess interactions between motivation and capability to support physiotherapists to facilitate survivors' uptake of PA as part of stroke recovery following rehabilitation. Our model provides unique information for development of a new assessment tool. The tool will enable physiotherapists to explore PA barriers with their patients in in-depth ways that physiotherapists have not previously had the skills to do. The tool will be linked to a

shared decision-making algorithm to guide therapists and survivors towards, evidence-based solutions to PA participation, individualised to survivors' situation and context. Assessing and addressing survivors' motivation and capability thus will enhance physiotherapists' skills in behaviour change and facilitate development of new strategies to translate PA intentions into actions. Developing and testing new stroke specific behavioural interventions to integrate our model with existing behaviour change interventions, and within appropriate socio-ecological frameworks requires future research. Collaborative approaches with survivors, their families and physiotherapists to ensure fit with current practice and diverse health and social care contexts are required. Furthermore, policy makers must provide accessible environments, transport and appropriate facilities to address pragmatic barriers to activity faced by survivors.

Limitations and Strengths

We sought diverse survivor views through purposive sampling; however nurses may have introduced recruitment bias by selecting survivors they considered most appropriate. Our structured topic guides sought to elicit comprehensive data however, participant accounts may have been reframed by retrospective bias. Nonetheless, this study enhances previous PA barriers research by providing a conceptual and pragmatic framework for physiotherapists' facilitation of PA.

Conclusion

Promoting PA after stroke requires evaluation of nuanced synergies between motivation and capability and a conceptual and pragmatic shift towards

interventions that achieve synergy between these concepts. Our model will support physiotherapists' assessment of barriers and facilitators to PA and inform development of person-centred interventions to promote survivors' sustained participation in PA for health and recovery after stroke.

Declarations

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The authors have no conflicts of interest to disclose.

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